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## Family Support and Involvement Team

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MAY 2024 - EDITED BY KATIE CRIBB AND SARAH LALLY

## FAMILY ADVOCACY & MENTAL HEALTH

Family advocacy means getting support from another person to help you express your views and wishes, and help you stand up for your rights. Family advocates speak for and act on behalf of others as they empower them.



Sometimes supporting your loved one requires you to acknowledge that you are not able and/or capable of providing them with what they need.

Please remember that if your loved one is at risk to themselves or others, the best resources are your local Emergency Department, and 911. In Vancouver, for non-emergencies please contact the Access and Assessment Center (AAC).

### AAC Contact Information

Hours: 7:30 am - 10:00 pm 7 days/week; 365 days/year

Phone: 604-675-3700

Address: Joseph & Rosalie Segal Family Health Centre, 803 West 12th Avenue, Level 1  
(at Willow between 12th and 10th)

## Land Acknowledgement

Vancouver Coastal facilities lie on the unceded and occupied lands and waterways of the fourteen First Nation communities of Heiltsuk, Kitasoo-Xai'xais, Lil'wat, Musqueam, N'Quatqua, Nuxalk, Samahquam, Sechelt, Skatin, Squamish, Tla'amin, Tsleil-Waututh, Wuikinuxv, and Xa'xtsa.

To find out more about the Indigenous land you reside on one option is the website [native-land.ca](http://native-land.ca)

## About us...

This Newsletter is brought to you by Vancouver Coastal Health's Family Support and Involvement Team. We assist families with resources, education, information, support, and with facilitating the inclusion of family in the care of their loved ones. We also work with patient and family partners to ensure that clients and families are involved in planning and decision making across Vancouver Coastal Health's Mental Health and Substance Use Services. You can find our contact information on the front page.

The *Family Connections Newsletter* is available electronically, direct to your email inbox. If you don't already receive *Family Connections* via email and would like to stay up-to-date about programs and services for families who are supporting a loved one with mental illness and/or substance use, sign up at [www.spotlightonmentalhealth.com](http://www.spotlightonmentalhealth.com)

By going to this website and clicking on the [Family](#) tab you can find our [Community Resource Guide for Families](#), Vancouver Coastal Health's [Family Involvement Policy](#) and much more.

Thanks for reading!



## Vancouver Family Advisory Committee (FAC)

*A Partnership with Vancouver Mental Health & Substance Use Services*

**Who Are We?** *We are Vancouver parents, siblings, adult children and friends of those living with serious mental illness and substance use. We are individuals with lived experience. We are community agency representatives, Mental Health & Substance Use professionals, and the VCH Family Support & Involvement (FSI) team. Together, we are the Family Advisory Committee.*

***The FAC provides a strong family perspective to improve services for our loved ones, and expand communication and supports for caregivers and families.***

If you feel inspired to join our efforts, or simply want to learn more about the FAC, please check out our webpage.

**Website:** <https://www.spotlightonmentalhealth.com/vancouver-family-advisory-committee/>

**To connect, email us at:** [VancouverFAC@vch.ca](mailto:VancouverFAC@vch.ca)

**We're always looking for new members!**

## OUR NEW TEAM MEMBER: Sarah Lally

### ***What is your background?***

I am originally from Galway, Ireland and I have been living in Vancouver for the past 8 years. I feel very fortunate to live and work in B.C. I am a registered Clinical Counsellor, alongside my role here at VCH, I also work part-time in a private practice in Vancouver. For the past 3 years I worked as a Coordinator and then I moved onto become an Assistant Manager in supported housing at MPA Society in the DTES. Prior to this I worked as a Project Assistant at Foundry. Before I moved to Vancouver I lived and worked supporting adults with mental health and substance use in Manchester, UK.



### ***What is the Community Family Support and Involvement Coordinator?***

The Community Family Support and Involvement Coordinator provides support to Vancouver community adult mental health and substance use services. The Coordinator works with the treatment teams to support family involvement and provide extra resources and support to families when needed.

### ***What are you looking forward to in this role?***

I am looking forward to working closely with families and providing space for families to be seen, heard and supported. I hope to be able to take some of the stress away from family members while the care for their loved ones. I look forward to navigating the system and promoting family centered care in community mental health and substance use.

### ***What else?***

I love the outdoors, nature keeps me in Vancouver. I completed a 42km trail run last fall, I am super proud of that! I enjoy camping, adventuring, travelling and sharing laughs with friends. I come from a large Irish family, I have 5 siblings. I grew up on a farm in the West Coast of Ireland and I have 14 nieces and nephews, whom I adore!

### ***How can we contact you?***

My email address is [sarah.lally@vch.ca](mailto:sarah.lally@vch.ca) and my contact phone number is 604-314-9032.

\*Please note my days of work are Monday-Wednesday, if you call me outside of my workdays, please leave a voicemail or send a text message and I will get back to you asap.

## **Advocacy in Care Teams**

*By Sarah Lally*

Service advocacy is defined as “working within systems to assist individuals and families in ensuring their needs are met” (VCH). VCH policy on Family Involvement with Mental Health and Addiction Services describes family involvement as a vital component of the framework of recovery which guides client care across VCH mental health and substance use services and programs. The policy outlines areas where care providers create opportunities for family members to engage with **service advocacy**:

*Care Providers will actively encourage and support Family Members to collaborate with Clients and Care Providers in all stages of care including assessment, treatment and discharge decisions, and decisions that may be determinants of health (e.g. housing, income, employment supports, etc.)*

### **Examples of advocacy**

- Helping your loved one explore their options
- Helping your loved one know their rights
- Providing information to your loved one so they can make an informed decision
- Helping your loved one make contact with supports and services
- Accompanying your loved one to an appointment
- Providing collateral to health teams
- Participation in policy development
- Community activism
- Collaboration on service planning
- Providing feedback to teams
- Participation on committees
- Participatory decision making
- Educating communities

### **Advocacy Burnout**

Burnout is a prevalent issue among advocates. Advocacy burnout is defined as a state of emotional, mental, and physical exhaustion caused by prolonged stress. The pressure to deliver results, the expectation of being available around the clock, and the ever-present urgency of their causes contribute to chronic stress. Poet Lindsay Young writes, resistance is not a one-lane highway. Maybe your lane is protesting, maybe your lane is organizing, maybe your lane is counselling, maybe your lane is art activism, maybe your lane is surviving the day. Do not feel guilty for not occupying every lane. Self-care includes advocating in ways that honor your health and safety needs.

### **Strategies to cope with advocacy burnout**

- Disentangle your sense of self from your advocacy work
- Voice your distress
- Learn to say no, even when you want to say yes

*Self care includes advocating in ways that honor your health and safety needs*

- Meditate
- Have a support system
- 1:1 counselling
- Connection with nature
- Body movement
- Support groups

### *Questions to consider when reflecting on your advocacy work*

1. What am I passionate about and how much energy do I want to put towards this passion?
2. How much time do I spend engaged with advocacy each week?
3. What are my advocacy strengths?
4. How does advocacy impact my relationship with others?
5. How do I feel when burnt out?
6. What does feeling healthy look like for me?

### *Sources*

Article titled *Engaging families and parent advocates in research on substance use and drug policy reform: Guiding principles from a Canadian community-academic partnership*

DOI for the article: <https://doi.org/10.1111/dar.13740>

Article titled *Advocacy in Mental Health* from the organization Mind. Mind is a UK-based national association for mental health.

Mind's website: <https://www.mind.org.uk>

Document titled the *Vancouver Coastal Health Population Health: Advocacy Guideline and Resources*

VCH's website: <https://www.vch.ca>

*Disentangle  
your sense  
of self from  
your advocacy work*



*As a family I am very proud of the fact that we have stuck by our daughter. Its not easy for families to hang in year after year.*

## **Interview with Holly Horwood, Family Member and Advocate**

**Conducted and written by Sarah Lally**

### **What advocacy work are you involved with?**

I separate advocacy into two streams, the stream I do directly on behalf of our daughter who has been involved with the system since the age of 16, she is now 41. This is much more nebulous. When she was younger and involved with community mental health teams, I would send a note every month before her meeting with her team, including her psychiatrist, outlining the things I thought went well that month, and the things we as a family were concerned about. It was all about communicating as a family, providing our perspective on her wellbeing. That's the main one, communication with team and doctors, staying on top of her progress, trying to ensure that we have a voice in her care and treatment, attending discharge meetings, just staying interested, which is harder to do than you would think when your loved one is off on a tangent and alienated from you.

Then there is the stream that I do for myself, as part of giving back, and in a way also to do the things that weren't successful with my daughter. Advocacy in the community. An example of this work is I just spent 4 days speaking to new police officers at the Justice Institute in New Westminster. I am part of a team with the B.C. Schizophrenia Society that's called Partnership Education Presentations (PEP). They go as a team comprised of an educator, someone with lived experience and a family member. Sometimes 2 people with lived experience. Some years I have done this three times per year, I used to do it with sheriffs. We do the PEP program with nurses & social workers too. For police we have 3 or 4 people present, for social workers we might just have 2 of us, depends on the audience. I have done this for around 12 years.

### **What education do you share at the PEP program?**

I focus (at least with police officers) on our experience as a family. The perspective of the family on police involvement over the years, for example, what they did well and what they didn't do well. For the social workers, it is a little more about communication as a family member. I always try give them a resume of our daughter's development and a little bit of background about the symptoms and challenges as a family, it's a little different depending on the audience. I have different talks prepared for different audience members.

### **How is it received?**

Very well! The police are primarily young and just starting out. The lived experience talks are the most profound for them, hearing from somebody who remembers being psychotic with police intervention. It can be quite emotional and moving actually. I just finished talks with one of the folks with lived experience, Bryn Ditmars, he is 45 now . I started out at UBC with him. Bryn is great, he is incredibly articulate! The next PEP series will be in July.

### **As an advocate, what are your most proud of?**

I have to say, as a family I am very proud of the fact that we have stuck by our daughter. Its not easy for families to hang in year after year, and my husband takes huge credit for it because he has been a rock, and our son too, he is age 37 now. I am very proud that we have stayed involved in her life because families go through such a rollercoaster, and it's not been easy. In terms of community advocacy, I am very proud to be involved with the PEP program and the role it plays in educating the

community. Not just in a professional way, for members of the community too if you see someone yelling and hearing voices, you just have a better understanding of what's going on. I can tell by the questions the nurses, social workers and police ask and the comments they make after. Its very rewarding!

### **As an advocate, what were you challenged with?**

It's a personal challenge because my daughter has limited insight into her own illness, it comes and goes and can be nonexistent. I've never been able to tell her what I do, she saw me once online, I think she would be very unhappy about it but it is something I do for me and for the sake of the bigger picture. Every now and then I do think about it, I am giving personal details about her, I don't name her but its her life that I am talking about and our reaction to it. It doesn't stop me but its just there as a thought. I speak at the heart and soul sessions (orientation for VCH mental health and substance use staff), over the years we have spoken to hundreds of different people, I am glad I am doing it. As I age, it is becoming a little more emotionally and physically exhausting. I will probably keep doing it for a while yet.

### **What has your experience been like in advocating for your daughter within her health team?**

Twice my daughter was discharged from extended leave by a review panel, both times prompted relapse and hospitalization and in 2010 she quit her job immediately after discharge. I wrote to the review board and to the Ministry of health and of course the response was very bureaucratic, I didn't expect much else, and so it wasn't overly rewarding. It was rewarding in the sense that I wanted them to see our perspective and I wanted them to know what happened because of that decision. One time I wrote to the head of psychiatry at St. Paul's hospital complaining and pointing out the difference in the reaction of different team members within the psychiatry teams. We had been told by one staff member that they couldn't talk to us for privacy reasons. I pointed out that it made sense and its best practice to talk to the family and get their perspective. We didn't expect them to tell us anything, most of the time we know more than they do anyway. The response there was fabulous, the head of psychiatry wrote back immediately, he arranged a meeting with a psychiatrist and in fact because of that I believe we had a role in changing the diagnosis from schizophrenia to schizoaffective disorder. I was noticing mood issues and I mentioned it and they seemed interested. This was a rewarding experience!



### **What worked well?**

Its important family members speak up if they feel they are being left out of the conversation, and are not receiving adequate communication from the professionals. I remember a discharge meeting where after at least 2 months in VGH we were never told who to talk to, who to connect with, nobody ever reached out to us but we were invited to the discharge meeting. I remember I got quite snotty with the social worker, he said "Hi I am Bob the Social Worker" and I said "Hi Bob the Social Worker, this is the first time I have ever met you", something to that affect.

Even though the community mental health teams never responded to my notes, because they couldn't, they were read and certainly with my daughters last hospitalization even though she had totally disconnected from her team, the psychiatrist understood my notes immediately, I wrote again outlining our concerns that she was psychotic again, and they responded with CAR 87 the next day, even though she was no longer connected.

### **How has your family advocacy been received by the professionals?**

Just by staying curious and staying interested in our daughter, I can reach out to somebody like Isabella Mori (former Family Support and Involvement Coordinator) and ask her a question like *when my daughter is disconnected from her care team and relapsing, who do we call, what do we do? Do we call her old team, do we call AAC?* Isabella directed me and that support is so important.

Another role of advocacy is participating in research studies and throwing our hat into that work.

I can say because I am used to writing, at least I was (I have been retired for many years) I felt comfortable writing to the head of St. Paul's hospital and the Ministry of Health even though I knew it was going nowhere. It was helpful for me! It helps me be organized when I put things down on paper, I see my daughter's symptoms and it makes it less emotional in a way. As a reporter we are trained not to be emotional, through writing I can look at everything almost through a 3<sup>rd</sup> person lens e.g. this month voices are more distracting etc.

### **How is advocating through writing different from advocating by speaking?**

Speaking is harder for me, but because I have done it for so long its become much easier. My memory is not great, so I like to have notes but now I am comfortable enough to detour and have side discussion. There was a committee set up by the provincial government a few years ago to look at the Police Act and I took part in that via zoom and the only thing they perked their ears up at was the fact that the BCSS does the PEP talks through the Justice Institute to hundreds of new recruits and I said that I feel it should be mandatory for every police officer in the province. This is one of the things I am proud of, I got their attention with that! Right now the PEP program is part of the crisis management/de-escalation program they take.



### **How has your advocacy journey impacted your relationship with others?**

I am not able to talk to my daughter about my advocacy (I would like to). As an advocate, parents envision a role for their loved one, standing up for their mental illness and speaking out. This is not exactly what's happening, its fine. My role with the FAC (Family Advisory Committee) has been very important to me, I've stepped back now, but it's broadened my range of friendships. A huge number of individuals have come into my life through family advocacy.

### **What is your fondest memory from your time in the FAC?**

When we put on the one-day family conferences, they had a variety of different themes e.g. housing. We had guest speakers, I would always get excited about organizing it, finding speakers and connecting with them. With COVID the conferences stopped, we held them for several years at the auditorium at VGH. In attendance you would get families, professionals, and folks with lived experience. The FAC organized the conferences along with staff.

### **What would you like to see next for the FAC?**

Its very important VCH has the FAC. I would like to see more families represented, I want to make sure there is always a family member speaking. I would like to see it retain its emphasis on the family, it's good to have folks with lived experience there but in my view it's not that committee's role. The committee's role is to represent the voice of the family.

### **What might you say to someone thinking of joining the FAC**

I would say wonderful, its so rewarding! It's good to feel you have a say in the wider umbrella of the delivery of



services. Our daughter never had issues with drug or alcohol abuse, I always felt that voice was important to have on the committee and for FAC membership its good to have a variety of family members with lived experience be part of the FAC.

### **How are you spending you time now?**

I am very involved with different projects; PEP program and I am happy to speak whenever the Heart & Soul talks take place. I am making myself available for individual projects as they come up.

Its so important professionals know the role that families have, that's why its important we stand up and remind them. I remember once I wrote a letter to a community mental health team because our daughter invited us to a family meeting, and this was rare. I couldn't attend because I had to work so my husband attended and he said the psychiatrist didn't reach out and shake his hand, it was very much us against them and this is so wrong. I wrote a letter and said we can do better, everybody can do better! Our daughter invited us, to go and be met with such a cold welcome was disconcerting and not useful for families, it doesn't make us feel welcomed and valued.

### **What does self care look like for you?**

For me, as much as possible, its keeping my role as a mother and our daughters role as our daughter in perspective. I cant live her life for her. We have been very fortunate that we have been able to provide housing for her, and we are very involved with her. Its important to recognize, particularly as I get older, how much I can handle, how much the family can handle and spread it around. My son takes a bit more of the phone calls and stress now, which is great. He is her only sibling. I left work early because it was getting heavy. There is a lot of impact on the family, I recognize it more now. I walk, I stretch, the usual.

We continue to learn which is interesting, we had a crisis just last week and we sat down and spoke to her and we were able to use some of the communication skills I have learned in support groups, for example the LEAP method. Sometimes its worse when she is relatively stable, which she has been for 1 year and we find this more challenging in different ways.

### **When did self care become important to you?**

Its been a constant evolution of knowing myself and knowing my daughter, its learning when I need self-care, i.e. when I was working and I retired early because it was a stressful time. That was a time of change for me, it brings its own challenges if your life revolves around your loved one, that is not good either. It's constantly trying to find a balance, this is important and that's constantly challenged, sometimes it's a little more her. We are going on vacation for 3 weeks and that will be lovely for my husband and I, but at the same time because she is doing more stuff these days, I tend to worry about her more. Again, its just keeping perspective, we can't live her life for her. I am always ready for the next crash, it's a possibility that's always there.

One of the biggest things for family members is for us to learn from other people with lived experience, going to talks with individuals with lived experience. I can see what our daughter is going through because of listening to them speak about their experience. As family members, I think it's crucial that we learn from others. I am blown away by how the patterns are the same, the illness is different in each person, no doubt, but there are very similar patterns.

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# Interview with Patience Lee, Older Adult Mental Health and Substance Use Social Worker

Conducted and Written by Katie Cribb

## Patience's Career Background and Current Role:

For the past 26 years, Patience has dedicated her career to social work. Initially, she worked as a home health case manager, before transitioning into working at the North Shore Older Adult MH team, specializing in Adult Guardianship. She then worked for five years in a private home-visiting practice for housebound elders until returning to Vancouver Coastal Health in 2012 to work at the newly opened Older Adult MHSU Unit at Willow Pavilion.

The Older Adult Unit, Willow Pavilion 5, is a specialized mental health service that provides care for older adults (65+) who are experiencing acute and complex dementia and/or other mental illness. Adults under the age of 65 with dementia and/or frailty may also receive care there. Over the past twelve years, Patience has supported the patients and their family members at Willow Pavilion 5.

As the unit's Social Worker, Patience is the main contact for the family members, including friends and caregivers, of the patients on Willow 5. She acts as the link between the health care team and the family. Family support and education are key aspects of her job. This includes providing information on topics such as dementia, frailty, and advance care planning (making wishes known and setting up legal options for the management of health care decision-making and finances). Recognizing the challenges that families face, Patience shares their experiences with the rest of the health care team and emphasizes the importance of treating families with compassion.

Additionally, Patience takes the lead in discharge planning, which includes coordinating referrals to long term care or other housing options. As well as connecting families to community supports such as government agencies, cultural resources, and income benefits. Patience supports her families with advocacy as well, which we will highlight later on with an example of how her advocacy and the advocacy of a family member came together to make a positive difference in one family's experience.

## Changes in Family Involvement due to Covid-19:

The pandemic forced the unit to enter the digital world in new ways, which has increased accessibility for some families. Many family team meetings have shifted to being virtual. This has allowed family members to join team meetings who might otherwise not been able to attend. Now, family members who do not live locally or have demanding work schedules are able to join in virtually. Similarly, going digital has made family visits possible for people who face physical barriers to getting to Willow Pavilion. Patience spoke about one patient who has family members in Central Europe. The ability to facetime has allowed them to connect regularly despite time differences and being an ocean away. Additionally, due to hearing loss, connecting over audio alone would have been difficult so being able to video chat has been a game changer for this family.

Adding to the unit's digital initiatives, a research project led by Clinical Nurse Specialist Dr. Lillian Hung brought two companion robots onto the unit. In partnership with the UBC Innovation in Dementia and Aging Lab, the project allowed families to use the robots to initiate contact with their loved-ones without staff intervention.



## Challenges that Families are Facing:

Patience has noticed an increase of patients with early onset dementia on the unit. Early onset dementia is experienced by people under 65 year old, which for many folks means they developed dementia before they retired from the workforce. In addition to the struggle of having a loved-one develop dementia, the loss of income from the partner who is now unable to work is very difficult for many families. Early onset dementia also means that their spouse or main caregiver is often younger and may have to balance caring for their young children, their partner with dementia, and their older parents, as well as still maintaining employment, now being the sole breadwinner.

No matter the family situation, many caregivers are under significant stress. Patience's strategies for supporting these families are to provide a listening ear (or eyes via email) so that they have place where they can vent their frustrations. When she is speaking to them, or in her email updates to family members, Patience likes to ensure caregivers are shown appreciation, thanks, and acknowledgement for all they do for their loved ones. Patience also tries to highlight the "small joy" updates when things do go well for their loved-ones during difficult times (ex: loved one enjoying a meal or sharing a story about their past) as caregivers are not able to be present 24/7 to see all of the positive moments. It is important to Patience to acknowledge all that caregivers do. Gentle, positive thoughts and energy can make such a difference in a difficult time.

## Examples of Family Advocacy:

Family members help us to get to know who their loved-one is as a person. They provide an insight on their loved-one's priorities and values which is instrumental to the care team. When making decisions about living with a risk of harm, knowing the desires of the patient and the family members is incredibly helpful. For example, the progression of a dementia can lead to difficulty swallowing. Some families have advocated for their loved one to be "eating or drinking at risk" so they can still enjoy the foods they prefer. For some people, this aspect of daily living is essential to maintain quality of life. In many cases, the team has been able to support the request to "eat at risk" and will put additional safety measures in place as indicated, such as having the patient avoid high risk foods or closely supervising meals.

Patience also shared the story of Marge (identity anonymized) as a powerful example of family advocacy. Marge had to leave work to be at home to care for her husband when his dementia progressed to the point where he was not safe to be left home alone. Without a steady income, she applied for and received Employment Insurance (EI). As part of the requirement to receive EI benefits, Marge began looking for evening work, with the plan that her adult son (who lived at home) would support his father in the evenings while she worked. However, due to a number of factors, including Covid-19, Marge was unable to gain employment while collecting EI.

Marge's case was reviewed by the federal government, and they determined that she misrepresented herself and was not available for work (as required) because she was at home as a caregiver for her husband. They sent her notice requiring her to pay back the \$10,000 in EI benefits. Marge got a supporting letter from her family doctor and tried to appeal the order to repay EI. There was liaison back and forth with the government and a Tribunal Hearing was scheduled. Marge contacted legal aid to request a lawyer to represent her at the Hearing but was denied (they

*Gentle, positive thoughts and energy can make such a difference in a difficult time.*

informed they only get involved after an unsuccessful Tribunal Hearing for further appeal).

At that time, Marge's husband was in care at Willow, and she was able to connect with Patience about what she was going through and inquired if Patience could support her at the Tribunal. Patience agreed with the approval of her leadership team and attended the tribunal together with Marge as an advocate. Both Patience and Marge shared with the adjudicator that it was necessary for Marge to care give for her husband during the time she was receiving EI. Patience emphasized that Marge's husband did not choose to develop dementia, and that Marge did not choose to become an unpaid/informal caregiver. Patience stated the importance of recognizing the role of caregivers, especially as the number of younger caregivers continues to rise. Patience advocated that the system needs to change to support the unique challenges and needs of the increasing number of caregivers who may still be employable but also need to care for their loved one.

Patience and Marge were successful in their advocacy and Marge won the appeal. This victory highlights how the role of caregivers needs to be recognized. Flexibility and accommodations need to be made in the expectations of caregiver availability for work. This in turn will help provide the much needed recognition and acknowledgement of family and other informal supports who continue to be the primary caregivers for the increasing numbers of people with dementia and other chronic illnesses.

### **Patience's Advice for Family Members:**

- Please prioritize your well-being and make time for yourself. Sometimes it helps to schedule it.
- Give yourself grace. I find caregivers are often too hard on themselves. We are all human.
- Please feel free to speak openly. You do not have to fear repercussions toward your loved one if you express any concerns regarding care provision. Our duty is to ensure your loved one feels safe and supported.
- Consider advance care planning for your loved one if not in place (and for you).
- We like to identify a main point of contact for the family (although as the social worker, I am happy to provide updates via a group email).
- Please provide copies of any legal documents e.g., POA or Rep Agreement to help guide health and financial/legal decision-making.
- We want to get your perspective on your loved and who they are as a person – to help us get to know them better and to help us ensure their comfort, safety, and well-being, and quality of life during their stay.

### **Patience's Recommended Resources:**

[My Voice: Expressing My Wishes for Future Health Care Treatment](#) - This advance care planning guide was created by the provincial government. You can use it to both learn about advance care planning and create your own advanced care plan. Available in eleven different languages

[Alzheimer Society of BC](#) - This BC-Based non-profit has a number of resources for both people living with dementia, their friends and family, and professionals. They have a wide range of supports including emotional support groups, educational trainings, and numerous informational resources.

[Nidus](#) - Nidus provides people in BC with education, support, and assistance with advance care planning and Representation Agreements. They have many helpful documents on their website as well as resources.

[The Public Guardian and Trustee of BC](#) - The PGT helps to protect the legal, financial, person and health care interests of adults who require assistance in decision-making. They have many resources and education documents linked on their site.

# Structural Advocacy

Written by Katie Cribb

Families advocating for their loved ones care can have a huge difference in the outcome and experience of their family member in care. While advocating for their loved ones, sometimes family members become aware of issues that are impacting more than just their loved one. This realization can lead to family members taking part in advocacy for systems level change.

System level advocacy refers to attempting to change policy, rules or laws within larger sociality structures such as government agencies, health authorities or organizations. Individuals can advocate for system level change alone, but may have more success as part of a group.

## Advocacy Roadmap

- Decide what you want
  - Find your sense of purpose
  - Set clear and specific goals
- Get the facts
  - Who can make the changes you want to see
  - How would the change benefit those in power (create a positive incentive to change)
  - Learn as much as you can about the government/ organization
  - What policy, rules, or laws are in place
  - What facts are needed to support the change
- Plan your advocacy strategy
- Gather support
  - Find others who are experiencing the same problem you are
  - Commit to seeing a change and putting in effort to support it
- Be firm and persistent



## Example of Advocacy Activities

- Organize a meeting for likeminded individuals (creating a base to draw from)
- Educate legislators (on issues that you would like to see addressed)
- Educate the public about the legislative process (who can they contact to make change on their behalf)
- Organize a rally
- Produce research on your community
- Public education sessions on nonpartisan voter education/ mobilization

Roadmap adapted from the presentation Systems Advocacy: What it is and how to do it by Joseph A. Rogers and Annette Williams. For more information visit <https://www.cmhsrp.uic.edu/download/systemsadvocacyppt.pdf>

*First on the list was identifying and addressing the challenges inherent in having family members included as partners in the care planning for their loved ones.*

## Overview of the Vancouver Family Advisory Committee

By Patti Zane (Chair)

The Vancouver Family Advisory Committee (the FAC) was formed in 2004. It was the result of a long process, some eight years of families working with and lobbying for improvements in the way families were treated within the system. In 2004, Kim Calsafferri, Regional Manager for Rehabilitation Services, formalized the Vancouver Mental Health Services Family Support and Involvement Plan. Two critical recommendations of this plan were the establishment of a Family Advisory Committee and the appointment of a Coordinator for Family Support and Involvement.

The FAC, for the next six years, worked to establish its role as an advisory body as well as the role of the family support coordinator within the system. The committee began to address the priorities of families that were identified in the Family Support and Involvement Plan. First on the list was identifying and addressing the challenges inherent in having family members included as partners in the care planning for their loved ones. It was a long, slow and at times frustrating process. We are grateful for the leadership of the family members whose efforts resulted in the creation of the committee and for their persistence and patience through challenging times.



The committee took action to meet other family needs identified in the plan. Family support groups were formed via contracted agencies such as BC Schizophrenia Society or Mood Disorders BC. The committee began sponsoring and organizing an annual Family Conference dedicated to educating about mental illnesses and navigating the health care system. Though it no longer hosts annual conferences “Expert Talks”, the creation of Isabella Mori, former Community Coordinator with the Family Support and Involvement Team, are ongoing.

The position of tertiary family and client support coordinator was established in 2011. Sharon Marmion in this position and Gloria Baker as the community coordinator established a cooperative working relationship. The role of the family coordinator grew, as did the need for family support services. In 2012, the FAC submitted a proposal for the creation of a Family Support and Involvement Team (the FSI) to consist of a Manager for Family Support and Involvement, and coordinators for Tertiary, Acute and Community services with a mission “to work collaboratively to establish a culture of family inclusion and involvement extending across acute, community and tertiary levels of care wherein service systems aim for navigational excellence and seamless transition as client and family needs change.”

The proposal was accepted, representing a significant step toward working across barriers created by administrative silos with in the health care system. A range of family support

services and staff development goals were set. The FSI team works diligently in conjunction with the FAC. The team's work has resulted in education programs for families and staff, family support groups, focus groups, family participation in program evaluations and redesign, reviews and policy development, the Family Connections newsletter, information brochures, handbooks and thousands of one to one contacts with family members in need of support.

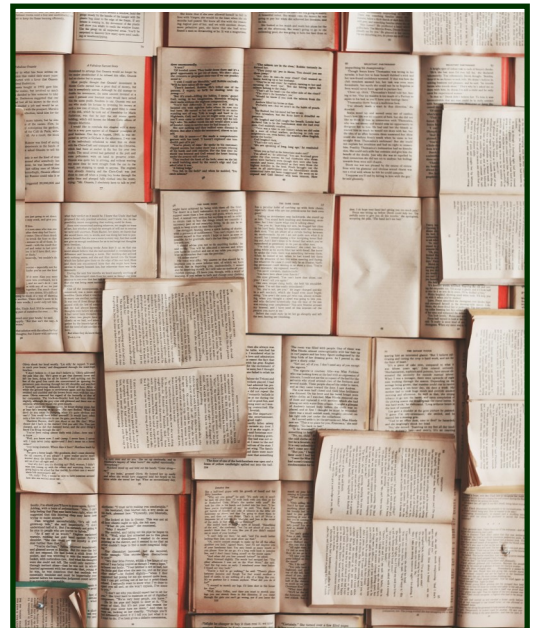
Two major changes in organizational structure and philosophy have taken place which significantly affected the work of the FAC. Firstly; there was the amalgamation (unification) of mental health and addiction services into what we now call Mental Health and Substance Use (MHSU) services. The FAC made efforts to identify needs of families specific to substance use and welcomed the potential to address the needs of those with concurrent disorders. The second major shift across the entire health authority was a shift to a philosophy of family and patient centred care, which supported many of the FAC's goals and objectives

In this atmosphere, VCH staff developed the Family Involvement Policy which addressed, at last, the number one priority of the family plan - the inclusion of families as partners in the care team. Ongoing consultation with and input from the FAC contributed to finalize this policy in 2013. It should be noted that this was an historical and most important achievement. The committee continues to worked with the FSI team participating in and monitoring the implementation and practical application of the policy across care settings at all levels.

In 2018 the committee formalized its mission defined by three pillars of focus: Advising (VCH professionals ask the FAC for advice), Advocacy (the FAC advocates with one group voice for issues of importance) and Education (for members, families and staff). These pillars are fundamental to the ongoing work of the FAC.

As advocates the committee has created and distributed a number of position papers and proposals including:

1. Position on the Model of Care (2013)
2. Commentary on Psychosocial Rehabilitative Services (2014)
3. Proposal for Establishment of Family Counseling Services (2015)
4. Response to the reorganization of Downtown Eastside Services (2016)
5. An invitation to work with Emergency Department professionals for better care for persons presenting in mental health crisis (2020)
6. Position on the Expansion of Car 87 and similar intervention services (2021)
7. Position on the Right to Involuntary Treatment (2021)



*We have come a long way from the time when families had to fight to be heard.*

8. Creating a navigation chart for families for the VCH website. (2022/23)
9. Position on MAiD MD SUMC\* legislation to balance the right to autonomy with the right to receive MHSU services \*Medial Assistance in Dying where a Mental Disorder is the Sole Underlying Medical Condition) (2023)

The committee has continued to grow its capacity as an advisory body, deepening communications with leadership, and steadily gaining respect as a valuable voice in patient centred care, providing input for a variety of initiatives such as:

- Updates to the Mental Health Act of BC and its associated Guide (2022/23)
- Forms overhaul for Involuntary Treatment (2022/23)
- Post hospital suicide prevention (2024)
- Increasing supportive and supported tertiary housing (2024)
- Development of education materials by Early Psychosis Intervention, and SAFER (suicide prevention)
- Clinical practice guidelines, Acute
- Development of admission and discharge protocol in Tertiary
- Educational brochures for families
- Segal hospital building design and planning
- Redevelopment ideas for Venture
- Virtual care services development
- Reviews of Acute, Tertiary and Community services
- Participated in the development of Experience of Care Surveys



The FAC's Terms of Reference state that "the Family Advisory Committee will represent the diverse voices of families and act in advisory, advocacy and educational roles to Vancouver Coastal Health, Mental Health and Substance Use Services". As VCH's focus on patient and family centred care develops, the role of the FAC evolves and grows as well. The committee provides a channel for the flow of information from families to care providers and for care providers to reach out to families for support and direction. We have come a long way from the time when families had to fight to be heard. We now participate as partners in respectful collaboration with VCH staff, grass roots organizations and the community at large.



## Tidbits from the Family Connections Support Group

This edition's Tidbits include a range of resources and information that we discussed in our VCH MHSU Family Connections Support groups.

### Variety of Local Resources:

#### **Gastown Vocational Services Supported Employment and Education Services**

- **Website:** <https://www.gvssupport.ca/>
- **Description:** GVS provides education and employment services to YYAP (youth and young adult program) 16-29 and an adults (30+) with a mental health diagnosis living in Vancouver.

#### **Mood Disorders Association of BC**

- **Website:** <https://mdabc.net/>
- **Description:** A nonprofit organization that provides treatment, support, education, and hope of recovery for people living with a mood disorder. The association has a family support group for Families and Friends of People with Bipolar Disorder.

### Variety of Educational Tools:

#### **Sashbear Foundation**

- **Website:** <https://sashbear.org/family-connections/>
- **Description:** Sashbear offers a free evidence-based 12-week program that provides education, skills training, and support for people who are in a relationship with someone who has emotion dysregulation or related problems.

#### **Center for Motivation and Change**

Website: <https://motivationandchange.com/>

Description: The center has a monthly group and great resources. One of the main clinicians at CMC is Jeffrey Foote, who wrote the book Beyond Addiction (mentioned in the link above). That book is a great companion book to I'm Not Sick I Don't Need Help.

### Book Suggestions:

#### **I am not Sick I Don't need help by Dr. Xavier Amador**

- **Website:** [www.DrAmador.com/books](http://www.DrAmador.com/books)
- **Description:** Dr. Amador's is a psychologist whose brother has schizophrenia, bi-polar disorder and addictions. Dr. Amador struggled to get his brother to accept his diagnosis and the treatment for it. This led Dr. Amador to conduct research on Anosognosia (lack of insight) as a symptom of schizophrenia. In this book he provides a plan on how to communicate with your family member when they have Anosognosia in a way that builds trust based on his research.

#### **The Gifts Of Imperfection by Brene Brown**

- **Website:** [brenebrown.com](http://brenebrown.com)
- **Description:** Brene Brown, PhD, wrote this book as a guide to a wholehearted life. Within this book Brene shares ten guideposts on the power of Wholehearted living—a way of engaging with the world from a place of worthiness .

*Websites,  
Resources,  
Books, rec-  
ommended  
reads!*



## The Family Connections Support Group

The **Family Support and Involvement Team** has a support group for family and friends of individuals with mental illness and/or substance use concerns. The group is co-facilitated by a Family Support & Involvement Coordinator and a family member.

We aim to create a welcoming and supportive space in which family members can share their experiences with each other and feel supported and strengthened in their efforts to help their loved ones. The group has a small educational component. Participants also receive twice-monthly emails with the contents of the educational part.

Like many other resources during COVID, we have moved our groups to ZOOM meetings. Family and supporters are free to attend on a regular basis or drop in as needed, like in our regular meetings. If you would like to receive an invite to our Support Group, please contact us and we will happily add you to our invite list!

We meet online on the following days & times:

**DATE:** Every first Thursday and third Monday of the month

**TIME:** 6:00 – 8:00 p.m.

**PLACE:** In the comfort of you own home

*\*We do not meet on STAT holidays.*

*Contact the Family Support and Involvement Team for the Zoom link at:*

[familyconnections@vch.ca](mailto:familyconnections@vch.ca)

**“Whatever you are struggling with, there are others out there who understand.”**

## MORE FAMILY SUPPORT GROUPS



### PLEASE CALL/EMAIL AHEAD TO CONFIRM DATES AND TIMES

**Parents Forever** – Support group for families of adults living with addiction. Group meets weekly via Zoom on Friday evenings. Contact Frances Kenny, 604-524-4230 or [fkenny@uniserve.com](mailto:fkenny@uniserve.com)

**SMART Recovery** meetings for families are back! Tuesdays 6:00-7:00pm, <https://smartrecovery.zoom.us/j/91012011101> Meeting ID: 910 1201 1101; Also search for a local meeting here: <https://meetings.smartrecovery.org/meetings/location/>

**BC Schizophrenia Society Family Support Groups** - for family members supporting someone with serious mental illness. Local listings of BCSS support groups across B.C. regions can be found here: <https://www.bcss.org/support/bcss-programs/family-support-groups/>. You can also contact the Coastal Manager @ 604-787-1814 or [coastmanager@bcss.org](mailto:coastmanager@bcss.org) for more details on the groups and to register.

**VCH Eating Disorder Program – Family & Friends Support Group** – for friends and family members of individuals living with an eating disorder. Contact Colleen @ 604-675-2531.

**Borderline Talks** - for individuals living with Borderline Personality Disorder (BPD) or Traits, and their loved ones. Zoom group every Sunday at 4pm. Check <https://bpdsupportgroup.wordpress.com/finding-help/>

**Pathways Serious Mental Illness** (formerly Northshore Schizophrenia Society) - weekly online support groups, and family to family education sessions. For more information on the next support group: <https://pathwayssmi.org/weekly-support-groups/>

**Pathways Clubhouse Chinese Family Support Group** – Catered to Chinese-speaking (Cantonese and Mandarin) individuals and families, who are caring for a loved one with mental health issues. 2nd Saturday of each month from 1:00pm to 4:00pm via Zoom. Part 1 (1:00pm-2:30pm) is a free talk delivered by a guest speaker and Part 2 (2:45pm-4:00pm) is a Heart to Heart Support Group Sharing. Additionally the 4th Saturday of each month has a face to face support group at the Pathways Clubhouse. Contact Lee Ma at [Lee.Ma@pathwaysclubhouse.com](mailto:Lee.Ma@pathwaysclubhouse.com) or 604-761-3723 for details.

**Alcoholics Anonymous**— Support groups for individuals looking to stop problem drinking. Local meeting locations can be found here: <https://www.aa.org/find-aa>